

9 Counseling Parents of Severely and Profoundly Handicapped Children

After mastering the material in this chapter, you should be able to

1. Understand and define severe and profound handicapping conditions.
2. Describe some typical needs of parents of severely and profoundly handicapped children.
3. Discuss counseling problems or concerns unique to mental retardation.
4. Understand and discuss various stages of parental reactions that are typical of parents of handicapped children.
5. Defend or refute *acceptance* of the handicapped child as a realistic and attainable parental goal.
6. Briefly list and describe the purposes and advantages of genetic counseling.
7. Discuss institutionalization in terms of its purpose, general guidelines, and placement decisions.
8. Identify and discuss applicable counseling strategies when working with parents of severely and profoundly retarded children.
9. From the parent point of view, understand and appreciate the complex phenomena and trauma often associated with being parents of a severely or profoundly handicapped child.

Times have changed. There has been an increase in concern regarding the rights of all individuals, including minorities such as the severely handicapped. Advocates for the severely handicapped are becoming larger in number, more experienced, and consequently more effective.

—Donna H. Lehr and Fredda Brown

Since options include some that are heavily weighted with ethical, moral, and emotional implications, there are some strong currents of controversy about genetic testing and counseling. Each individual and couple will have to evaluate personal, family, religious, and cultural values.

—Dorothy Dolph Zeyen

Helping parents of severely and profoundly handicapped children to become aware of their concerns and the search for realistic solutions presents a challenge to any helper. For example, guilt is a common parental reaction to diagnosis of their severely or moderately handicapped child. Parents have a tendency to blame themselves for their child's handicapping condition. The parent may feel he or she has actually done something that caused the problem, or the parent may experience vague yet deep-seated guilt feelings that can cause a great deal of anguish and turmoil.

The ways parents handle guilt may take many directions, but the most common appear to be (a) to blame themselves (which takes its toll on their own adjustment), (b) to switch the blame to someone else (an unhealthy practice because parents end up finding fault with others, sometimes those who are treating the child), (c) to completely deny the existence or the seriousness of the handicap, (d) to begin to blame each other (taken to an extreme, the mother may wonder if the genetic defect came from the father's relatives, or her mother-in-law), and (e) to resort to "shopping behavior," making visits to a number of different professionals or clinics hoping to find a "cure" for their child's handicap.

In this context, let us now examine in greater detail some principles and ideas related to working with these parents.

DEFINING SEVERE AND PROFOUND HANDICAPPING CONDITIONS

In Chapter Eight, the AAMD classification system was used to make some broad comparisons and distinctions between mild, moderate, severe, and profound retardation. Severely and profoundly retarded children were said to experience a low level of functioning. Their education programming, then, is based on functional daily skills (Hallahan & Kauffman, 1982).

Expressing a similar yet broader perspective, Hardman, Drew, and Egan (1984) have noted the following:

Persons with severe and profound disorders generally have multiple impairments that transcend the characteristics associated with a single disabling condition. The characteristics of people with mental retardation range from being able to develop skills that will facilitate independence within their environment, to being unable to take care of themselves at all. The severely and profoundly retarded exhibit serious deficiencies in cognitive development, physical development, and communication skills. In addition, greater intellectual deficiency tends to result in a higher incidence of compounding sensory dysfunction. (p. 175)

Cartwright, Cartwright, and Ward (1981) note that the severely retarded represent about 3.5 percent of all retarded persons, and the profoundly retarded (those who score below 20 on standardized intelligence tests) comprise about 1 percent of the entire range of retarded persons. They also point out that in contrast to mild retardation, severe retardation is usually diagnosed early in a child's life.

MEETING THE NEEDS OF PARENTS OF SEVERELY AND PROFOUNDLY HANDICAPPED CHILDREN

Dean (1975) made this observation of parent needs:

Although parents of handicapped children differ in many ways, there are certain experiences they share in common. Among these are a lack of adequate emotional support; a lack of information on where to turn for appropriate educational services after diagnosis, evaluation, and presentation have occurred; and a lack of information on how to change laws, rules, and regulations which exclude handicapped children from needed services. These life experiences which are common to parents of any handicapped child are even more important to parents of severely handicapped children. The type and quality of professional help available and the amount and type of parental cooperation will ultimately determine the strength and direction of the helping relationship. (p. 527)

Gordon (1977) sums up parental needs:

Parents need guidance, they need comfort, and they need to be periodically freed from their heavy burden and lonely burden of providing for a child whose care requires more than the usual amount of parenting and nurturing.

The needs of the children are great; the needs of the family are even greater.

The needs of the children are frequently met; the needs of the family are too seldom recognized or satisfied. (p. 61)

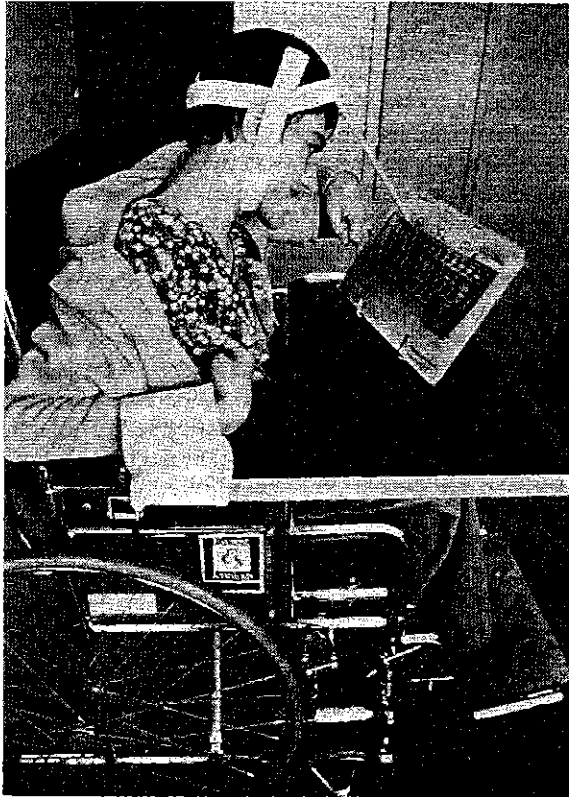
What specifically can you do as a helper to offer support and comfort to families of severely handicapped children? Gordon (1977) offers four suggestions:

1. They [parents] need service from the first moment their child is identified as exceptional—service delivered *to them* rather than service they have to seek, service organized *for them* rather than service that they have to mobilize for themselves.
2. Parents of handicapped children need other parents of handicapped children with whom to speak, if only to know, as one parent put it, "that other mothers can live [through this] and can survive with these awful burdens, and sometimes can even smile and laugh."
3. Parents need professionals who are sound academically, stable emotionally, and ready to face the situation with them, empathize with them, and translate for them a realistic picture of the handicapped child's current status, as well as projections that can be made, while admitting that there are some projections that cannot yet be made about the child's future development and potential.
4. Perhaps the greatest initial assistance that can be offered to parents is respect for their feelings of shock, fear, and anxiety. Parents need to express feelings, rather than merely listen to reassurances that everything will turn out all right. (p. 62-63)

Ehlers, Prothero, and Lagone (1982) suggest six action steps designed to help parents cope:

1. Help parents to be more objective about both their child and the child's handicap.
2. Help parents to predict their child's future behavior—what behaviors will the child outgrow and what behaviors can they expect to continue?
3. Help parents to assimilate ideas and techniques for various problem situations common to families of a retarded child.
4. Help parents (as well as the entire family) to see that the handicapped child has the same physical, sexual, recreational, and educational needs as they do.
5. Help parents to discover all the community resources available to them (e.g., clinics, evaluation centers, parents' groups, workshops, and educational institutions for the retarded).
6. Help parents to devise a method of keeping track of the handicapped person's progress toward the set goals and objectives. (pp. 350-351)

In discussing experiences unique to families of severely handicapped persons, Lyon and Preis (1983), identified three areas of significant impact on the family: psychological/emotional, financial, and practical/logistical. The psychological or emotional area concerns parental and family reactions to the birth of a handicapped child. These reactions will be discussed in greater detail later in this chapter. Lyon and Preis point out that many parents have difficulty paying for the numerous services needed for their children.



One of the counselor's goals is to help parents appreciate their child's potentialities and accept their child's limitations.

Finally, the practical side of meeting the needs of the handicapped child, maintaining satisfying marital relationships, fulfilling professional commitments, and the mundane concerns of daily living puts strain on a family. Complex family relationships are a major part of the child's adjustment. Farber (1968) comments that the role of the child in the family may be more important than the professional diagnosis of the child as a handicapped individual.

COUNSELING PROBLEMS UNIQUE TO MENTAL RETARDATION

To both the layman and professional, comprehending mental retardation is in many respects more perplexing and elusive than other types of handicapping conditions. Ross (1964) illustrates this by the following:

Even though the sighted person cannot possibly know how it feels to be blind, he can nevertheless imagine what it is like by walking blindfolded into a strange room. He can similarly imagine what it is like to be deaf or otherwise physically impaired. On the other hand, it is totally impossible to achieve any degree of empathy for the state of the mentally defective for we cannot suspend our higher mental processes or temporarily cancel everything we learned. Because of its nature, mental retardation offers some peculiar characteristics and problems which require enumeration. (p. 100)

The Diagnosis

The parents' most vulnerable time is when the child is first diagnosed. Parents usually are unable to face this problem realistically or even look at it constructively. They especially need help in handling their emotions and in planning for the child. Counseling these parents involves encouraging them to realistically assess the changes that will occur and to determine a proper course of direction. Stone (1948) suggested some guidelines for judging parental awareness. Even today these three levels can help the counselor determine parents' initial awareness and provide criteria for measuring their level of awareness.

Considerable awareness

1. The parent states that the child is retarded.
2. The parent recognizes the limitations of any treatment.
3. The parent requests information about suitable care and training, usually placement in an institution.

Partial awareness

1. The parent describes the symptoms of retardation with questions about the causes.
2. The parent hopes for improvement but fears that treatment will not be successful.
3. The parent questions his own ability to cope with the problems.
4. The worker evaluates him as having partial awareness of the child's real problem.

Minimal awareness

1. The parent refuses to recognize that certain characteristic behavior is abnormal.
2. The parent blames causes other than retardation for the symptoms.
3. The parent believes that treatment will produce a "normal" child. (p. 363)

Burton (1976) comments that the physician often fulfills the initial role of counselor. This counseling level is frequently inadequate, contributing to the crisis because the physician is unable to communicate effectively. Ehlers (1964) concludes that physicians have difficulty communicating the

circumstances of retardation to families, frequently frightening and confusing the parents. Welch (1981) vividly illustrates this point.

My baby was already a few minutes old and I had not yet held her. But I heard her crying, and as I turned my head I saw a crowd of people around an incubator. "What's wrong, what's wrong?" I continued to ask. I must have repeated that question several times before a woman came into view over my head and said, "Your baby is retarded." Then she disappeared.

The trauma that I experienced immediately after my daughter's birth might have been lessened if the obstetrician, or anyone else in the room, had responded to me when I first asked about the baby. They did not have to instantly tell me that she was retarded. But someone should at least have said, "Give us one moment and we will be right with you" or "We will be right with you as soon as we complete the emergency procedures." (p. 525)

Welch makes an eloquent plea that professionals learn to be compassionate, thoughtful listeners and be able to respond to the emotional needs of the family, not just provide information. This is sound advice for all who counsel with parents of the severely and profoundly retarded.

Lee (1984) discusses new research that indicates another problem in the patient-doctor relationship—failing to communicate clearly. Boston University researchers questioned 800 women and doctors after they had met for genetic counseling sessions. The goal of the sessions was to educate patients about birth defects. The sessions lasted 40 to 60 minutes each, about three times longer than most doctor/patient consultations. The results of the Boston study indicated that only 16.7 percent of the doctors knew when the decision to have a child was the woman's main concern. Only 15.2 percent of the doctors knew when amniocentesis was the patient's primary concern. The results clearly show that doctors and patients just aren't communicating. Perhaps part of the problem is that patients don't ask the right questions out of fear or ignorance and, though doctors are trained to diagnose, they aren't trained to educate.

PARENTAL REACTIONS TO MENTAL RETARDATION

The first problem that many parents of mentally retarded children face is accepting the fact that *their* child is intellectually retarded. Our achievement-oriented society and the ambition of many parents to see their children lead happy, successful lives often compound the problem. Parents often see their children as extensions of themselves and are naturally bitterly disappointed to learn that their child has intellectual limitations. Acceptance is frequently cited as the first counseling goal, yet Roos (1977) challenges this assumption:

Two popular objectives in counseling parents of the retarded are getting parents to accept mental retardation and lifting the depression which seems to be a

common parental reaction. Unfortunately, neither of these objectives is realistic. While parents may fully understand that their child is mentally retarded, it is unrealistic to expect them to accept this situation with blandness and equanimity; our society places too high a value on intelligence. (p. 73)

When their child's condition is diagnosed, parents of the severely and profoundly retarded may express their feelings in many ways. Wolfensberger (1967) cites only a few of the possible reactions:

Alarm, ambivalence, anger, anguish, anxiety, avoidance, bewilderment, bitterness, catastrophic reaction, confusion, death wishes, denial, depression, despair, disappointment, disbelief, disassociation, embarrassment, envy, fear, financial worries, grief, guilt, helplessness, identification, immobility, impulses to destroy the child, lethargy, mourning, over-identification, pain, projection, puzzlement, regret, rejection, remorse, self-blame, self-pity, shame, shock, sorrow, suicidal impulses, trauma, etc.

Stages of Parental Reaction

There has been an ever-increasing body of literature about parental stages of adjustment after learning their child has a handicapping condition. Heward and Orlansky (1984) state that

There is no question that the birth of a handicapped child or the discovery that a child has a disability is an intense and traumatic event. Parents can react in widely different ways, and most do go through an adjustment process trying to work their way through. But we see two problems with promoting the idea of "stages of adjustment." First, it is easy to assume that all parents must pass through a similar sequence of stages and that time is the most important variable in adjustment. Second, the stages parents are said to pass through have a distinct psychiatric flavor; professionals may mistakenly assume parents are maladjusted. Some educators seem to assume that all parents of handicapped children need counseling. (p. 432)

Despite this criticism, certain types of reactions are common and warrant additional discussion. None of these reactions is peculiar to parents in general or to the parents of defective children; they are common reactions to frustration and conflict. The average parent will display or experience these reactions to nondisabled children as a normal part of family life. It is helpful to the parents of handicapped children to be aware of the universality of their reaction (Telford & Sawrey, 1981).

Reviewing the literature on this subject suggests that parents tend to go through a series of stages after learning their child is handicapped. Hardman, Drew, and Egan (1984) note that the most predictable and common reaction to the birth of a child with a disorder is depression marked by grief or mourning. Burton (1976) claims that this depression is frequently compounded by a lack of information, or misinformation, and Wolfensberger

(1967) concluded that parents often felt guilty when the retardation was diagnosed at birth.

Mandell and Fiscus (1981) acknowledge the importance of grieving the loss of having a normal, healthy child. They suggest a five-stage process for both professionals and society to acknowledge. The stages are as follows:

1. Denial
Parents often refuse to believe the existence of a handicap, the permanence of it, or its impact on the life of the entire family.
2. Guilt
Parents' guilt is manifested in one of three ways. The least common is attaching the cause of the child's handicap to some specific past action. A second form of guilt is the belief that "bad things happen to bad people; therefore, I am bad." A third form—the most frequently found and the most difficult to deal with—is the belief that the impaired child is a just punishment for something the parent has done.
3. Depression
Depression is anger turned inward. Parents punish themselves because they cannot do what they want to do—make the child nonhandicapped.
4. Anger
Anger occurs on two levels. The first is often expressed as "Why me?" The other is usually unspoken and frequently is displaced onto the spouse, a sibling, or a professional. This silent anger is actually hatred for the handicapped child.
5. Bargaining
The last stage is bargaining with science, with God, or with anyone to cure the child. It is a "last ditch" attempt by parents to change their circumstances.

Mandell and Fiscus emphasize that not all parents go through all stages—the intensity and duration of each stage varies from parent to parent.

A much earlier framework illustrating stages of parental reaction, again a five-step process, was proposed by Rosen (1955): (1) an awareness that a serious problem exists; (2) recognition of what the problem is; (3) a search for the cause; (4) a search for a solution; and (5) acceptance of the problem.

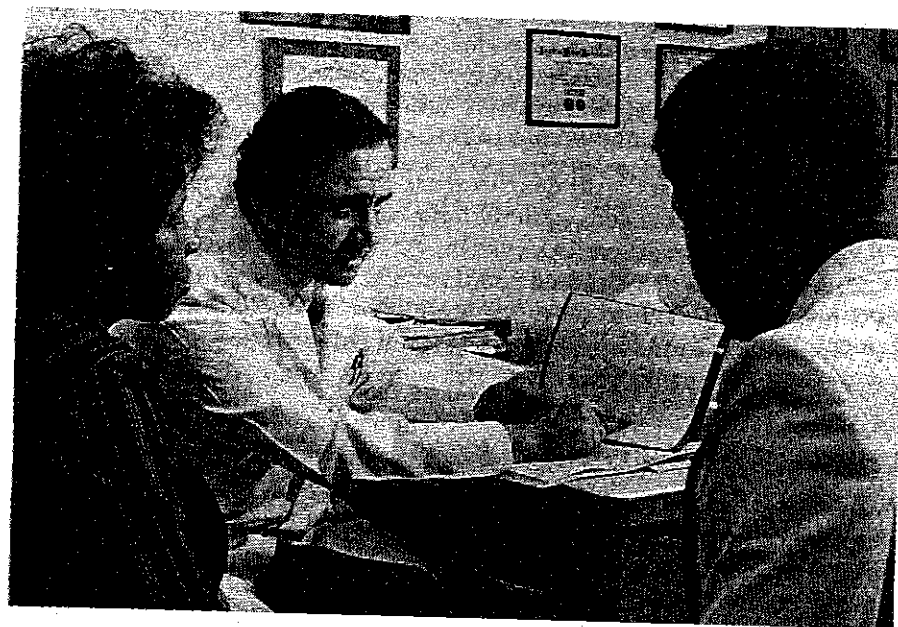
Blacher (1984) examined the existing literature for patterns or stages of parental adjustment to the birth of a child with handicaps. His purpose was to provide a brief overview of this literature and raise some practical questions to guide further research. Specifically, (a) How were the stages derived?, (b) Are the stages reliable indicators of parental adjustment?, and (c) Is there an alternative approach to the study of parental adjustment that might yield more useful information for people wishing to help parents of handicapped children? Blacher's detailed analysis presents views from both sides of the question of whether or not parents follow a sequence of adjustment, finally achieving acceptance. Blacher's conclusions and summary are worth our noting.

The question of whether sequential stages of parental adjustment to a handicapped child are clinically and scientifically derived fact, or an artifact of researchers' attempts to perpetuate ideas from the literature, remains to be determined. To date, the stages approach to understanding parental adjustment to a handicapped child has provided a useful heuristic. There remains the need for an instrument to be used by professionals who work with these parents (whether as parent trainers, counselors, school psychologists, or educational evaluators), to ascertain the parents' current level of awareness and adjustment and make practical programming and placement decisions accordingly. (p. 67)

PARENTS HAVE QUESTIONS

After diagnosis, the stress borne by parents of severely handicapped children leads to many questions. Feelings of inadequacy, shame, defensiveness, loss of self-respect, and increased ambivalence are typical parental reactions. The intensity of these reactions often leads the parents to ask more questions about the actual dimensions and severity of the child's disability.

Attwell and Clabby (1971) identified 231 specific questions that parents of mentally retarded children were likely to ask. We should again remember



Genetic counseling can provide parents with reliable and valuable information.

that the specific nature of a parent's questions will always vary according to such variables as impact on the family, the degree of retardation, the parents' level of comprehension and understanding of their child's condition, and the ability to cope with their unexpected, ongoing burden. A representative sampling of these questions follows:

- ☐ What is the cause of our child's retardation?
- ☐ How severely retarded is he (she)?
- ☐ Why did this have to happen to us?
- ☐ Is it safe to have another child?
- ☐ Does the genetic background of one parent contribute more to the retardation of a child than that of the other person?
- ☐ Can mental retardation be "cured"?
- ☐ I cannot help but pity my child. Is this wrong?
- ☐ If our retarded child lives at home, will it affect our normal child adversely?
- ☐ How shall we explain him (or her) to our normal children?
- ☐ How shall we explain him (or her) to our relatives, friends, and neighbors?
- ☐ Should we belong to a parent organization? What are the advantages of belonging to a parent group? (pp. 15-87)

In looking at what the future holds for families of the severely retarded, McLeod (1985) makes the following comment:

When a child has an IQ of 70 or below—the point at which people are considered mentally retarded—parents must abandon many dreams and adjust to their child's severely limited prospects. But how limited must such a life be? Must their child live forever in an institution or, if at home, be permanently dependent on the family or the state? (p. 42)

McLeod states that "attitudes toward the abilities of people with mental retardation have changed—quietly but profoundly" (p. 44). She quotes the Association for Retarded Citizens who now estimate that about 75 percent of mentally retarded children could become self-supporting adults with the proper training. Ten to 15 percent could be partially self-supporting. Using McLeod's information, helpers may be able to offer hope, encouragement, and support to parents of the severely retarded.

GENETIC COUNSELING

Steward and Orlansky (1984) define genetic counseling as a discussion between a specially trained medical counselor and prospective parents about the possibilities of giving birth to a handicapped child. Genetic counseling can provide parents with valuable, reliable information and can determine whether or not their child will be born with a chromosomal abnormality such as Down's syndrome. According to Hoemann and Briga (1981), the goal of genetic counseling is to provide accurate information to clients so

that they can make an informed decision about having children.

A medical procedure called *amniocentesis* (am-nee-oh-sen-tee-sus) is a frequently used prenatal diagnosis that is especially useful to parents who have already given birth to a child with a chromosomal abnormality, or when the mother falls within a high-risk group. Beeson and Douglas (1983) note that amniocentesis is also appropriate for pregnancies in families with a history of diagnosable genetic disease such as Tay Sachs disease, alpha-thalassemia, sickle-cell anemia, and many inborn errors of metabolism. In fact, approximately 30 specific genetic disorders can be identified prior to birth.

Amniocentesis is performed during the second trimester of pregnancy (16-18 weeks from the first day of the last menstrual period). Amniocentesis is about a 10- to 15-minute outpatient procedure that involves extracting a sample of fluid from the amniotic sac surrounding the fetus. The fluid, which contains fetal cells, is then analyzed for chromosomal abnormalities.

A relatively new and promising procedure for detecting chromosomal abnormalities is now being tested in the United States, since amniocentesis cannot be performed before the 16th week of pregnancy (Begley, 1984). Another two or three weeks are needed for tests, leaving the mother little time to consider a second-trimester abortion if the fetus is abnormal. The new technique, called chorionic villus biopsy, provides an alternative. This procedure, performed in the 10th week of pregnancy, uses extra-embryonic tissue that is genetically identical to the fetus' cells. The tissue can then be analyzed for the extra chromosome typical of Down's Syndrome, probed with DNA to identify sickle-cell anemia, or ground up to test for Tay Sachs. We are on the threshold of new advances in technology, biology, and medicine that will expand our scope of knowledge and understanding of genetic counseling.

INSTITUTIONALIZATION/ DEINSTITUTIONALIZATION

The professional helper should be prepared to discuss institutionalization (the separation of child and family) to the parents. Robinson and Robinson (1976) comment on four factors making institutionalization a likelihood.

1. Level of retardation
Institutions are being utilized for the most retarded segments of the population.
2. Ethnic background and economic status
Within each IQ category, children in residential facilities tend to belong to the economically and socially least adequate families.

3. Behavioral problems

The incidence of behavior problems is seen as an important factor leading to placement.

4. Family characteristics

Signs of stress and maladjustment have been found in families who seek placement for their children. (pp. 436-438)

To help parents resolve this traumatic problem, Gearheart and Litton (1975) offer some logical guidelines. They suggest that institutionalization is needed when (a) vital educational, medical, or behavioral controls are unattainable at home, (b) the emotional and/or physical welfare of the family is seriously threatened, and (c) the child is a proven threat to self or society. Gearheart and Litton warn against institutional placement based on diagnostic labels and suggest that placement outside the home be on a trial basis.

Voelker (1975) remarks that there is no stock answer to the question of placing the child outside the home because of the complexity and many variables of each situation. He believes it is important to consider if there are community resources to assist the parents and the child, if the family can accept and successfully integrate the handicapped child into its structure, if the financial income of the family is sufficient to provide adequately for the handicapped child as well as other members of the family, and if the severity of the child's handicap will make permanent care and supervision inevitable.

Batshaw and Perret (1981) propose the following guidelines for institutionalization:

First, institutionalization should be viewed as a last resort to be considered only after less restrictive environments have failed. Conversely, institutionalization should not be ruled out as a possibility for the child with severe multiple handicaps.

Second, the decision should be a joint one involving both parents and professionals caring for the child. This eases the burden on everyone.

Third, if at all possible, the parents should continue to be involved with the child, visiting him and taking him home on weekends.

Finally, the need for institutionalization should be reviewed by all concerned at regular intervals and a less restrictive environment chosen should this become appropriate. (p. 361)

Institutionalization in the United States has had a controversial history. According to Blatt and Kaplan (1966), during the 1960s institutions were exposed as abusive environments that dehumanized both residents and staff. Kneedler, Hallahan, and Kauffman (1984) note that this justified criticism sparked a movement toward deinstitutionalization—moving the handicapped from large institutions to smaller community houses. This movement is still emphasized today for the severely and profoundly retarded.

Heward and Orlansky (1984) comment that "Fortunately, no new large

state institutions for the retarded are presently on the drawing boards, and a variety of alternative residential placements are coming into reality" (p. 89). These alternatives to large institutions include regional facilities, day care centers, group homes, apartment living, outpatient clinics, foster care, and even adoptive services for the handicapped.

Regardless of the type and quality of the facility, the decision to place a child outside the home is a difficult, agonizing experience for the parents of the handicapped child.

Gross (1980) says this about making such a decision:

I felt all alone with the questions that were in my head. On the one hand, how could I reject my own flesh and blood? What if Saul didn't get proper care? How would I know if he did not? I had read enough books and seen enough doctors to know that Saul would fare much better at home. How was I ever going to live with such guilt?

On the other hand, was I prepared to care for a sickly child? Would I be willing to give up my numerous activities and interests for a perpetual toddler? Was it fair to David, or any other children I might have, to bring Saul home? What about my marriage—could it stand the strain? Could I? (p. 114)

Blaska (1984) says this about the difficult decision to institutionalize:

It became apparent to us that we could no longer meet David's needs at home. If we were going to provide the best possible environment for our son where he could develop to his maximum capacity, it was time for him to leave home.

Although intellectually the decision was made, the thought of packing his things and knowing he would never live with us again was almost more than I could endure. During the two weeks following our decision, I cried every time I thought of David leaving. Since David did not know yet of our plans and would not understand my tears, I would seek refuge in the locked bathroom. I tried to be strong. (p. 52)

COUNSELING STRATEGIES

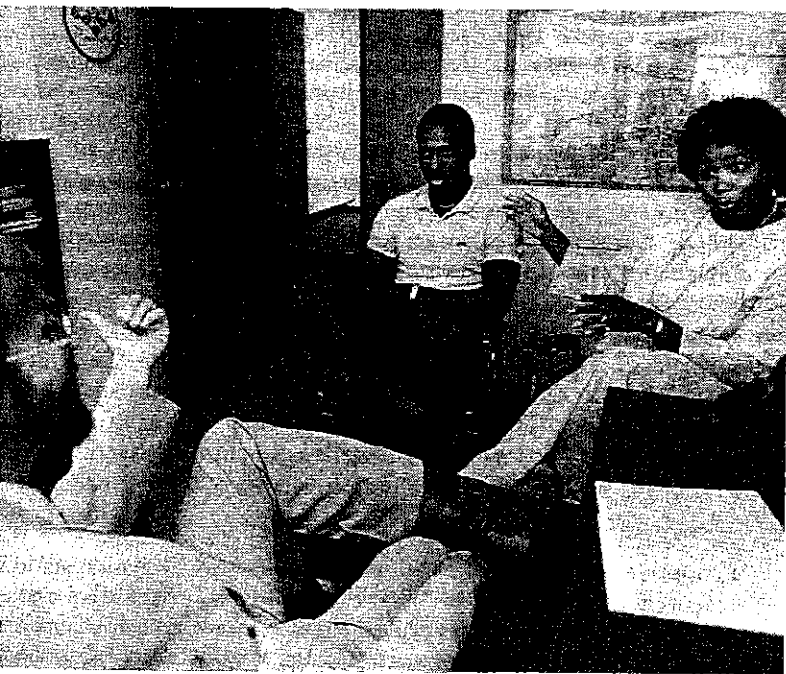
Parents of a handicapped child will normally find themselves bombarded with advice and suggestions from friends, relatives, educators, psychologists, and medical doctors. To effectively help these parents, remember that

1. under no circumstances should you pretend to fully understand what the parents are experiencing. You can, of course, be sensitive and empathic toward these parents; however, unless you have personally experienced their situation, be honest with parents. We don't understand because we can't.
2. Within your capabilities, you can and should offer appropriate and meaningful information, comfort, and support to parents of severely and profoundly handicapped children.

A study by Fairfield (1983) suggests that counseling parents of handicapped children challenges the counselor to determine the attitudes, feelings, reactions, and concerns of the parents to maximize parental coping. Fairfield's summary of her study should be noted:

In order to facilitate the family's adjustment to having a child with a genetic disease, the counselor needs to be able to understand clearly the true feelings of parents regarding their handicapped child. Pinpointing parental concerns permits the counselor to predict future difficulties for individual families and makes it possible to intervene appropriately and to prevent such problems from occurring. The present study suggests that soliciting and interpreting early recollections from the parents of a genetically disabled child can aid the counselor in a clinical setting to:

1. Distinguish between apparent coping and real coping.
2. Determine the most critical concern of the parents.
3. Uncover feelings that lie beneath a parent's denial of the child's condition.
4. Reveal hidden guilt of a parent.
5. Predict parental overprotectiveness of a child.



is a challenge to the counselor to determine parental attitudes, feelings, reactions and concerns.

6. Clarify parental expectations and fears regarding the heritability of the child's condition.
7. Encourage positive parental coping. (pp. 411, 415)

Seligman and Seligman (1980) stress the value of parental attitudes and feelings and offer the following practical suggestions:

When considering a particular family situation, often the most useful vantage point is that of the parent. It would be extremely beneficial if professionals would value the parents' perspective about a particular child and family. It is necessary for the professional to view parental perceptions as adding to the information they already have, instead of considering them contradictory. Professionals who base their evaluations on the information received from other professionals, their own observations, the child, and the parents are in the strongest position to be helpful. (p. 513)

In a discussion of parents and families of persons with severe mental retardation, Fredericks (1985) comments:

- ☐ One of the major factors that seems to influence initial parental reactions to a child with severe mental retardation is the manner in which the information is passed to the parents by the professional who makes the diagnosis. (p. 144)
- ☐ Parents are involved with professionals throughout the child's life and the parent-professional relationship is always one of reciprocity; sometimes the relationship creates profitable tension and other times critical stress. (p. 148)
- ☐ Although today most parent-professional interactions are occurring at the preschool and school levels, there is another group of parents for whom professionals need to exhibit a deep sensitivity. Many parents of adults who are severely retarded and who have never been institutionalized are tired, somewhat discouraged, and disappointed. (p. 147)
- ☐ The need for better communication and better understanding between professional and parent can lessen the long range impact of having a handicapped child on parents and families. A supportive professional environment can lessen stresses and sadnesses which parents carry with them as they strive to help their severely retarded child function more normally in the environment. (p. 147)

COUNSELING INTERVENTION

Trout (1983) stresses the importance of carefully studying families of handicapped children over time "to understand how—or whether—the baby is finally integrated, and how long-term developmental and psychiatric outcome relates to early social and experimenal variables." He adds that

In the meantime, we surely know enough to turn our educational, pediatric, psychological, and family medical attentions in some helpful directions. We can give parents and siblings clear and concise diagnostic, prognostic, and

etiological information. We can organize contact with a reliably available support system, in the hospital, for every family delivering a baby in trouble. The system could include a perinatal coach, a group of other parents of sick and handicapped babies, or just a family down the street with a similarly diagnosed child. We can offer families time to grieve, and we can support them in that experience largely by the time we offer and by what we do not say. We can understand and tolerate ambivalence without being shocked by it, and setting aside our need to wrap up major issues for families with a trite phrase ("It will be better later." "This is just a test of your strength, and you'll be fine." "Of course you don't hate her—you're just tired.") We can understand the dynamics of parental sabotage of our educational and medical interventions. We may find that our patience with such parental uncooperativeness is increased when we attempt to learn how it has been for the family, and the chances for the success of our work with the baby will be increased thereby. (pp. 346-347)

Opirhory and Peters (1982) believe early counseling helps parents adjust and accept the total situation and gives a positive outlook for future rehabilitation. Trust and confidence are important as well.

The parents have the right to know that their anxiety is normal. They may feel that their baby is still fragile. They may doubt their own competence in adequately caring for their child. With adequate reassurance and teaching from the counselor or other health professionals, the parents will come to trust themselves because of their counselor's confidence in them. The parents must receive continual support and reinforcement from the counselor as well as information regarding possible feelings and concerns that they may experience once their infant is home. In this way, the counselor has provided comprehensive and holistic care to the family of a less than perfect newborn and has facilitated their adjustment to and unconditional acceptance of their infant. (p. 454)

The personal account of Patty McGill Smith (1984),* a parent of a handicapped child, may help you to look at counseling parents on two levels: (1) from the parent viewpoint, particularly noting feelings and attitudes, and (2) from the helper's viewpoint, who may be called on to offer counseling to other parents who need support and understanding.

If you have recently learned that your child is developmentally delayed or has a handicapping condition, which either is or is not completely defined, this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a handicap, I was devastated—and so confused that I recall little else about those first days other than the heartbreak.

*Adapted from Patty McGill Smith, "You are not alone: For parents when they learn that their child has a handicap," March, 1984, *National Information Center for Handicapped Children and Youth*.

Many things can be done to help a parent through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the common reactions that occur.

On learning that their child may have a handicap, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and with this enormous challenge:

1. Denial
"This cannot be happening to me, to my child, to our family."
2. Anger
May be directed toward the medical personnel who were involved in providing the information about the child's problem. Early on, it seems that the anger is so intense that it touches almost anyone.
3. Feelings of grief and inexplicable loss
4. Fear
People often fear the unknown more than they fear the known. Having the complete diagnosis and future prospects can be easier than uncertainty. Parents fear that the child's condition will be the very worst that it possibly could be. There is also fear of society's rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers and sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.
5. Guilt
Guilt and concern about whether the parents themselves have caused the problem: "Did I do something to cause this? Am I being punished for having done this? Did I take care of myself when I was pregnant? Did my wife take good care of herself when she was pregnant?" Much self-reproach and remorse can stem from questioning the causes of the handicap.
6. Confusion
As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such a trauma, information can seem garbled and distorted. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving.
7. Powerlessness
You cannot change the fact that your child is handicapped, yet parents want to feel competent and capable of handling their own life situations. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others.
8. Disappointment
That a child is not perfect poses a threat to many parents' egos and a challenge to their value system.
9. Rejection
Rejection can be directed toward the child, the parents, or the situation.

personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child—a feeling that many parents report at their deepest points of depression.

Not all parents go through every one of these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise so that they will know that *they are not alone*. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

Seek the assistance of another parent

My first recommendation is to try to find another parent of a handicapped child, preferably one who has chosen to be a parent helper, and seek his or her assistance. The National Information Center for Handicapped Children and Youth has listings of parent groups that will reach out and help you.

Talk with your mate

Over the years, I have discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength.

Rely on positive sources in your life

One positive source of strength and wisdom might be your minister, priest, or rabbi. Another might be a good friend or a counselor. Go to those who have been a strength before in your life. Find the new sources that you need now.

Take one day at a time

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the "what if's" and "what then's" of the future. Good things continue to happen each day. Take time to "smell the roses."

Learn the terminology

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation for a minute and ask the person to explain the meaning.

Seek information

Some parents seek virtually "tons" of information; others are not so persistent. The important thing is that you request *accurate* information. You should not be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child.

Do not be intimidated

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is

occurring. Remember, this is your child, and the situation has a profound effect on your life and on your child's future.

Do not be afraid to show emotion

So many parents, especially dads, repress their emotions because they believe it to be a sign of weakness to let people know how badly they are feeling. The strongest fathers of handicapped children whom I know are not afraid to show their emotions.

Learn to deal with bitterness and anger

Ultimately, bitterness and anger will hurt you a great deal more than they will affect those toward whom the anger is directed. It is very valuable to be able to recognize your anger and then let go of it. Life is better when you are feeling positive. You will be better equipped to meet these new challenges when bitter feelings are no longer draining your energies and initiative.

Adopt a grateful attitude

It is hard to remain angry when one is grateful. Sometimes, when everything seems to be going wrong, it is difficult to find a cause for gratitude. However, in the scheme of things, if you look around and count your blessings, perhaps positive feelings can overtake the more negative ones.

Maintain a positive outlook

A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is truly always a positive side to whatever is occurring. For example, when my child was found to be handicapped, one of the other things pointed out to me was that she was (and still is) a very healthy child.

Keep in touch with reality

To stay in touch with reality is to accept life the way it is. To stay in touch with reality is also to recognize that there are some things that we can change and other things that we cannot change.

Remember that time is on your side

Time heals many wounds. This does not mean that living with and raising a child who has problems will be easy, but it is fair to say that, as time passes, a great deal can be done to alleviate the problem.

Find programs for your child

Even for those living in isolated areas of our country, assistance is available to help you with whatever problems you are having. While finding programs for your handicapped child, keep in mind that programs are also available for the rest of your family, too.

Take care of yourself

In times of stress, each person reacts in his or her own way. A few universal recommendations may help: get sufficient rest; eat as well as you can; take time for yourself; reach out to others for emotional support.

Avoid pity

Self-pity, the experience of pity from self,

are actually disabling. Pity is not what is needed. Empathy, which is the ability to feel *with* another person, is the attitude to be encouraged.

Avoid judgments

During this period, parents may become judgmental about the way people are reacting toward them or toward their child. Others may sometimes react inappropriately, but you need not use too much energy in being concerned over those who are not able to respond in ways that you might prefer.

Keep daily routines as normal as possible

My mother once told me, "When a problem arises and you don't know what to do, then do whatever it was that you were going to do anyway." Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

Remember that this is your child

This person is your child, first and foremost. Granted, your child's development may be different from that of other children, but this does not make your child less valuable, less human, less important, or less in need of your love and parenting. Love and enjoy your child. The child comes first; the handicapping condition is second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

Recognize that you are not alone

The feeling of isolation at the time of diagnosis is almost a universal feeling among parents. You can diminish these feelings by recognizing that they have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone.

CHAPTER SUMMARY

This chapter has provided a basis and rationale for counselors as they work with parents of severely and profoundly handicapped children. The emotional reactions to the diagnosis of a handicapped child form the foundation of this chapter. You should remember that it does little good (and possibly irreparable harm) to focus on the cause of the handicap or to allow one member of the family to place blame on another family member.

A handicapped child typically places parents and the family under stress at different points in their lives. The diagnosis is usually the first stressful occasion. Parents often pass through a typical sequence of reactions such as shock, denial, sadness, fear, anger, and finally adaptation or the restoration of equilibrium. Helpers should not conclude that all parents go through the same stages. These are emotions and reactions that parents may or may

not experience in sequential order or at all. Parental reactions and stages are complex interactions among and between family members that find expression in feelings, attitudes, and beliefs.

Caring and knowledgeable professionals can help parents meet the basic and fundamental needs of providing and caring for their handicapped child. Present a description of what can be done for their child immediately, what services are available now, and what may be needed in the future. You are not limited to providing practical information—providing parents with psychological support and understanding is just as vital. To accomplish this task, recognize the parents as individuals with their own set of needs and feelings. Respect parents' feelings, offer support and psychological comfort, and be flexible in that each situation is unique.

ACTIVITIES, EXERCISES, AND IDEAS FOR REFLECTION AND DISCUSSION

- As a helper, how might you respond to the following situations assuming that a child has been diagnosed as severely or profoundly retarded or handicapped? What dominant themes or ideas would likely be stressed?
 - The parents blame themselves for their child's condition.
 - The parents believe God is responsible for their child's condition.
 - The parents feel that they have "let others down," especially the immediate family and significant others.
 - The parents dwell on and continue to search for the cause of their child's condition.
 - As a form of denial, the parents continue to search for a cure for their child. (This is often referred to as *shopping behavior*.)
 - The parents are reluctant (or afraid) to discuss their feelings with you or any other helper.
 - The parents convey to you that they feel helpless and that their situation looks hopeless.
 - The parents say to you, "You just don't know what we're going through, you haven't been there!"
 - The parents (who live in a very small community) say that they have read about "support systems" that can offer understanding and information from other sources.
 - The parents express doubts about their ability to lead normal, productive, and rewarding lives.
- Of the following responses, choose *one* that would help the most to bring about parental acceptance of their severely handicapped child's behavior?
 - "No one is perfect."
 - "There is room for everyone in a democracy."
 - "We all have a contribution to make to society."
 - "Everyone has weaknesses."
 - "If we all work together, the child will have a successful life."
 - None of the above. If so, why?

g. Your response _____

- When working with parents of severely and profoundly handicapped children, is it important for professionals to be able to recognize individual differences among families and to be flexible in helping mothers, fathers, and siblings? Why or why not?

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